



Published in final edited form as:

*Int Rev Psychiatry*. 2012 February ; 24(1): 70–78. doi:10.3109/09540261.2012.659659.

## Recovery in the USA: From politics to peer support

Laysha Ostrow<sup>1</sup> and Neal Adams<sup>2</sup>

<sup>1</sup>Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

<sup>2</sup>California Institute for Mental Health, Sacramento, California, USA

### Abstract

Efforts to transform the mental health service delivery system to a more consumer-driven and recovery-orientated approach has its roots in a somewhat radical anti-psychiatry and civil-rights movement dating back to the 1970s. This grass-roots effort gained momentum and credibility with Harding's landmark study published in 1988 followed by the work of Anthony et al. from Boston University in beginning to define the term 'recovery' In 1998 the Office of the US Surgeon General issued its first report on mental health, and this critical view of the shortcomings of the existing service system set the stage for the 2003 President's New Freedom Commission and its recommendations for recovery-orientated systems transformation. The recovery movement has evolved from a more radical view in the early days, to participatory involvement in systems, to returning to alternative models of care that are more independent. Now as more peer specialists work in systems, there is an increased emphasis on non-medical alternatives and the cycle continues. Regardless, recovery, self-determination, choice, etc. are always at the centre. This paper notes the interesting cycles of recovery-orientation and how they spin around the values/tenets of the movement's early roots.

### Introduction

It has been argued that mental health treatment has evolved, especially over the past half-century through incremental steps, guided by scientific advances, driven by an ideology of recovery, community integration, and service user empowerment (Goldman et al., 2008). At the same time, individuals with a diagnosis of a mental illness too often feel that they have been labelled and given a message by the treatment system and their providers of hopelessness about their lives, unending disability and inevitable deterioration; the goal of a meaningful life as an integrated member of the community still has not yet been achieved in a real way for many people. Understanding the disparity between professional perspectives and the experience of consumers can perhaps provide the most accurate history of recovery in the USA. That understanding builds on consumers' first-person accounts of hearing critical and limiting messages from providers, family members and society at large, overcoming challenges posed by a treatment system that views them as disabled, and finding their own voice and vision for recovery for themselves and their peers.

© 2012 Institute of Psychiatry

Correspondence: Laysha Ostrow, NIMH Pre-doctoral Training Fellow, Department of Mental Health, Johns Hopkins School of Public Health, 624 N. Broadway Hampton House, Baltimore, Maryland 21205, USA. Tel: +617-999-4207, Fax: +410-955-9088. [lostrow@jhsph.edu](mailto:lostrow@jhsph.edu).

**Declaration of interest:** The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

The outcomes that have traditionally been valued in the US mental health system are those related to reduction of symptoms and improvement in functioning. Symptoms and functioning are not incompatible with recovery, but models of recovery as an outcome challenge many traditional values of psychiatry (Corrigan et al., 2004). The first studies that challenged the prevailing wisdom as well as public perception and provided clear evidence of recovery from mental illness were published in the 1980s by Courtenay Harding (Harding et al., 1987). These findings have been validated by many other studies such as the paper by Calabrese and Corrigan (2005) showing that recovery does occur for a large percentage of people diagnosed with schizophrenia, which is often regarded as the most serious of all mental disorders. Using both measures of psychosocial functioning (e.g. employment and residential status) and symptoms/psychopathology, these studies demonstrate the ability of some people to lead a fulfilling life despite the persistence of symptoms or having remission of symptoms (NFC, 2003).

Shifts in policy have been informed by the perspective and experience of the individual; Arthur Frank (1995) describes three forms of narrative that tell the story of recovery from illness. The first is the 'restitution narrative' in which the person tells their story by framing the course of their illness as a return. The second is the 'chaos narrative', which is difficult to tell because the person is in the midst of their illness, and imagines never getting better. The person cannot see their recovery, although it may exist. The third narrative style that Frank describes is the 'quest narrative' and is the fundamental basis for the development of the recovery movement in the USA. The quest narrative endows the person with the fortitude to challenge their suffering, learn from it, and use their experience to their advantage. The quest narrative is the one that gives the person voice to tell their individual story. This makes the quest narrative like the rising of the phoenix – the symbol of reinvention (Frank, 1995). The quest makes you more than you have been, having been 'interrupted' by mental illness, and opening oneself to becoming a better, healthier, more empowered person.

It has been said that an acceptable definition of the concept or experience of recovery was most formally established in the 1990s by Anthony (1993) as follows:

[recovery is] a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (p. 527)

This is similar to the timeline of the development of the recovery concept in New Zealand and other countries (O'Hagan, this issue, pp. 56 – 63).

However, there is good evidence that an understanding of recovery has existed for even longer in the USA's consumer movement. The mental patients' liberation movement grew up around deinstitutionalization in the late 1960s and 1970s. People who had been institutionalized and labelled as mentally ill began to organize to assert and protect their civil rights as people and as patients. They felt oppressed by the traditional, historic mental health system, most prominently institutional 'care', but also by the power dynamic between many mental health professionals and themselves (Chamberlin, 1990). The mental patients' liberation movement sought to establish alternatives to what was cast as a paternalistic mental health system so that 'rather than becoming passive recipients of institutional "care", troubled people would be helped to see the strong and positive aspects of themselves as they, in turn, help others' (Chamberlin, 1978, p. 19). Judi Chamberlin's book, *On Our Own* (1978), was seminal in defining and describing the movement, its foundations, and its objectives. This has been viewed by some as part of a larger civil rights and advocacy movement for people with a wide range of disabilities and challenges.

The movement by people with mental illnesses has been divided within itself by an orientation toward, or against, psychiatry; from that the self-assigned labels of 'consumer', 'survivor' or 'ex-patient' (often abbreviated as c/s/x) have emerged. Traditionally in psychiatry, a 'good' patient was a person who complied with treatment as prescribed by a doctor or other professional, acknowledged their disability as life-long, and accepted their dependence on a system that provided increasingly limited benefits and services that seemed to foster disability rather than promote the potential to return to a full life in the community. As consumers began to challenge these views, a vision of recovery developed, and recovery-orientated systems, self-directed care and shared decision-making became essential issues of advocacy as well as research and policy priorities.

The Mental Patients' Liberation Movement (who called themselves 'ex-patients') were very much influenced by the anti-psychiatry movement that began in the 1960s by professionals that held the belief that psychiatry was making people worse, not better (McLean, 2000). The first efforts to restructure the mental health system were led by professionals including Thomas Szasz, R.D. Laing, and Thomas Scheff, among others (Tomes, 2006). There were multiple theories offered to explain this: Szasz was a psychiatrist who said that mental illness was a 'myth' (and really constituted 'problems in living') which was invented by the 'pseudoscience' of psychiatry (Szasz, 1974). Laing, also a psychiatrist, took existential philosophy and applied it to mental illness, and believed that schizophrenia was a 'split' in a person's relationship with the world and with oneself, and that people should be allowed to experience their 'insanity' (Laing, 1962). Scheff was a sociologist who was a proponent of labelling theory, which said that mental illness was a social role created by diagnosing people (Scheff, 1966).

Anti-psychiatry was a movement of intellectuals, not patients, that joined the other movements of the 1960s in challenging the establishment (Rissmiller & Rissmiller, 2006). The modern day consumer movement denies most likeness to the anti-psychiatry movement (Van Tosh, 2006). Yet, both can be considered civil rights movements, and link their emergence to others including the gay pride movement and the women's liberation movement amongst others. People labelled with mental illness felt that they were victims of 'mentalism' – fear of and prejudice against people with mental illness (Chamberlin, 1978). In the mental health liberation movement there was a bifurcation between two groups: those who identified themselves as 'consumers' were somewhat more accepting of the traditional 'medical model' of treatment and tried to influence the established mainstream system. In contrast, the survivor movement was dedicated to developing alternatives to the traditional mental health system (McLean, 2000). Despite those fundamental differences, both groups rejected the politics of psychiatric control over people with mental illnesses; the consumer movement rejected it in favour of a more collaborative approach with mental health professionals (Van Tosh, 2006).

Beginning in the 1970s, consumers claimed their right to special insight into the system and into the experience of mental illness (Tomes, 2006). Although there were early peer support groups that organized around the notion of recovery from mental illness (Barker, 2003), the c/s/x movement did not really exist until deinstitutionalization, when a significant number of people who had been held for extended periods in state hospitals began to be discharged and returned to communities (Goldman et al., 1983). The subsequent influence of consumers has been a consequence of deinstitutionalization, and should not be mistaken as a driver of that policy (Tomes, 2006). Since that time, the consumer movement has tried to be a powerful interest group in the development of mental health policy. While people have come together for a common purpose, each individual remains free to choose their own label based upon their own experience and perspective. Fragmentation in ideology between 'ex-

patients', 'survivors', and 'consumers' is minor enough to allow them to be united in promoting empowerment and equality for people with, or labelled with, mental illnesses.

As the mental health system attempted to respond to calls for patients' rights and reform, in many ways, people with mental illnesses felt a sense of 'co-optation' of their fight for a more just system (Brown, 1985). They rejected the support of professionals and even government funding at first because of a wariness about co-optation (McLean, 2000). The degree to which mental health professionals and non-consumers, particularly family members, should be involved in consumer efforts is one issue that has at times divided survivors and consumers (Tomes, 2006). One distinction between the groups is that consumers fought for the right to treatment, while ex-patients fought for the right to refuse treatment – both reflected in the judicial actions of the time, including landmark cases such as Wyatt versus Stickney (1971) and O'Connor versus Donaldson (1974). Consumer involvement in policy and service delivery has always been essential to the recovery ideology. The Community Support Program (one of the earliest forms of community-based care) involved consumers, who expressed hope for new systems that would be consumer orientated (NIMH, 1982, pp. 11 – 13); Other consumers at this time expressed their rejection of the mental health profession which had caused them so much anguish (NIMH, 1982, pp. 34 – 35). Regardless, this was the first time that consumers began to have a seat at the table and more of a voice in the mental health system.

During this same period, the efforts of families to assert their own sense of improved mental health services led to many conflicts with the consumer and anti-psychiatry movements. The family movement spawned the National Alliance for the Mentally Ill (NAMI), an advocacy group which became much more financially and politically powerful than the consumer movement. NAMI's support of a biologically based explanation of mental illness as well as forced treatment for consumers if necessary were points of profound difference (McLean, 2000). This created many ideological conflicts between family members and consumers. While there was much interaction between different interest groups approaching the same problem with similar goals, they became somewhat divided into different factions based on identity (e.g. intellectual, mental health professional, consumer, ex-patient, legal professional, etc.).

The consumer movement continued to grow over the 1980s and 1990s, and is seen by some as really coming of age during this period (Manderscheid, 2008). 'Alternatives' a national conference for consumers intended to be the start of a nationwide consumer organization was first held in 1985 (McLean, 2000). Alternatives is now held annually, and is the largest national congregation of consumers in the USA. These early efforts to organize the consumer movement benefited from support by the federal Substance Abuse and Mental Health Services Administration (SAMHSA) but the ongoing role of this agency has diminished as it became increasingly marginalized and underfunded (McLean, 2000).

The Surgeon General's report on mental illness in 1999 was the first national policy document to assert that recovery in mental illness is possible, that it should be the focus of services, and the existing system would require substantial changes in order to meet these goals (Office of the Surgeon General, 1999). In 2003, under an Executive Order from then President George Bush, the New Freedom Commission (NFC) was formed to provide a thorough assessment of the country's mental health treatment needs and service delivery system. The Commission found that the system was 'fragmented' and 'in shambles' and called for a 'fundamental transformation' of the mental health system (NFC, 2003). Recovery was defined by the Commission as 'the process in which people are able to live, work, learn, and participate fully in their communities' (NFC, 2003, p. 5). Recovery has also been defined by the SAMHSA as encompassing hope, empowerment, self-direction,

individualization/person-centredness,holism,peer support, a focus on strengths, respect, responsibility, and the right to a non-linear recovery journey (SAMHSA, 2004). The NFC report included six goals and 19 specific recommendations; perhaps the most important, Goal 2, called for the mental health system to be consumer-driven, and clearly supported a recovery vision and recovery-orientated systems of care. However, although other countries have had similar commissions that were translated into action plans for mental health systems (Piat, this issue, pp. 19 – 28) the NFC report and the idea of transformation were never systematically operationalized and the recommendations implemented across state systems.

The call for transformation of the mental health system garnered support from virtually all stakeholder groups including consumers, family members, professionals and researchers, state mental health agencies, and along with the executive and legislative branches of the federal government. However, the concept of transformation was ephemeral to most people and the central goal of recovery proved difficult to define and understand (Davidson et al., 2006). Transformation really calls for a fundamental if not paradigmatic change in the infrastructure and performance of the mental health system. Such an effort requires the involvement of all stakeholders, most importantly consumers, and at the same time it is difficult to envision. How do we see a system that is not fragmented when it has always been so? How do we know consumers are adequately involved when they have always been marginalized? How do we define recovery-orientation when each individual, despite ‘consensus’ among ‘experts’ (SAMHSA, 2004), must define recovery for themselves? These are questions that a transformed system must ultimately answer if the changes are to be made successful and responsive to stakeholder expectations.

Still, there is not a complete alignment of consumer and provider perspectives and understanding. The provider community tends to see recovery as conforming to a restitution narrative as described earlier – the expectation is that individuals diagnosed with a mental illness should return to their former role and functioning. For most consumers, however, recovery comes from a quest narrative. It was the ability of consumers to begin to be able to communicate a recovery narrative to the larger community that helped legitimize recovery as a personal and political motivation for change. From this perspective, recovery not only embodies the notion that a person has their own quest narrative about self-hood and wellness, but also the implicit expectation to engage in full citizenship. The substance abuse field has acknowledged the importance of citizenship in recovery, as has Alcoholics Anonymous, which requires giving back to the community as peers as the 12th step of recovery. From this perspective, engagement in society and citizenship are essential for recovery and wellness. It remains unclear what role, if any, the formal service delivery should play in this personal process of growth and change.

It is perhaps noteworthy that the mental health field does seem to have a well developed and equivalent concept of responsibility to society or peers to make a difference in the world beyond the notion of taking responsibility for one’s own recovery. As a field, there has been limited discussion of the responsibilities of citizenship, although people seem to be quick to debate the privileges. An article by Ware and Hopper (Ware et al., 2007) about individuals with psychiatric disabilities states:

Historically, the rights of persons with psychotic illness have been restricted on the grounds of mental incompetence, reducing them to second-class citizens or citizens of programs serving ‘special populations’. On the same grounds, they have been exempted from social and personal responsibility.

Perhaps examining these dimensions of the recovery concept will come to shape values, attitudes, expectations and practice over the coming decade as the US mental health system



continues to evolve and better understand the complexity of recovery both for the individual as well as the service delivery system and the society as a whole.

## Where we are today: Continued progress and challenges

Across the USA, there is a growing consensus among all stakeholders that recovery is the essential outcome of care/services and that recovery-orientated systems must include some specific key structures and processes to support those outcomes (Davidson et al., 2006; Onken et al., 2003). This is not unlike what occurred in Australia, where recovery moved from being an individualized experience well understood by consumers to becoming part of national policy (Oades, this issue, pp. 5 – 10), In the USA the term ‘stakeholders’ is meant to include consumer groups (e.g. National Coalition on Mental Health Recovery), family members (e.g. National Alliance on Mental Illness (NAMI)), rehabilitation providers (e.g. United States Psychiatric Rehabilitation Association (USPRA)), and state mental health authorities (e.g. National Association of State Mental Health Program Directors (NASMHPD)). Today, all of these stakeholders and their respective organizations work to promote mental health recovery as evidenced by their mission statements, their websites and advocacy activities. There has been some concern that the mental health professions have not been fully supportive of recovery practice as reflected in their education and training. Recently the American Psychiatric Association, the American Psychological Association, the American Psychiatric Nurses Association, and the Council for Social Work Education were all awarded SAMHSA grants to develop training materials to adopt ‘Recovery into Practice’. Therefore, the provider perspective is changing, and with more workforce training, a recovery-orientated approach and a new set of treatment expectations may become a basic component of education for providers, and hopefully increase ‘buy-in’ by these stakeholders as well.

That recovery exists, as defined by the SAMHSA National Consensus Statement (SAMHSA, 2004) and the New Freedom Commission (NFC, 2003) is now not really a debate. Much of the principles, vision, and values of recovery are supported in the aim of the Institute of Medicine’s *Improving the Quality of Health Care for Mental and Substance-Use Conditions* report of patient-centredness as a quality indicator in mental health treatment (IOM, 2006). Patient-centred care and shared decision-making can be seen as synonymous with recovery practice as it includes tailoring care to individual needs, respect for patients, and focusing on the individuals’ quality of life, goals and wellness in the context of their life as a whole person (Adams & Grieder, 2005).

In 2012, people feel empowered; they have hope; they want individualized and person-centred care. Recovery-as-practice is moving into traditional services. However, the public, and some provider groups, may hold on to stigma that projects the belief that recovery from serious mental illness is not possible, or is simply defined as symptom remission and return to full functioning. The American Psychiatric Association has adopted a position statement on recovery that includes many essential elements, but also includes a remaining focus on coping and symptoms: ‘The concept of recovery focuses on increasing the patient’s ability to successfully cope with life’s challenges and to *successfully manage their symptoms*’ (APA, 2005). On-going stigma is an issue that consumers, providers, family members, and other supporters of recovery have to refute. Promoting the idea of recovery as defined here should be a public health priority in order to overcome stigma, and to validate the idea of using recovery as a goal for clinical and community-based services. If we do not have funding, public support, and workforce training geared toward recovery, then it makes it difficult to promote recovery consistently and across settings.

However, around the world, there is an increasing demand from policy-makers, payers, regulators and patients for empirical proof of efficacy and effectiveness in all of medical practice. Against this backdrop, the lack of a definition for recovery beyond an individualized process, and the challenges in quantifying and evaluating outcomes, is a problem that has the potential to limit further advances in recovery-orientated research, policy and practice. Yet, individuals who have experienced recovery do not doubt its existence or the meaning of the recovery journey (Nielsen-Bohlman, 2004).

Some of the lack of empirical data supporting recovery is due to the lack of research on recovery-orientated services and studies using recovery as an outcome (Chamberlin cited in Campbell-Orde et al., 2005) and more research is needed if the gains of the past are to be sustained and advanced. One challenge is the fundamental divide and difference of opinion in the mental health field about what outcomes should be a priority for researching and evaluating mental health services, with recovery often falling short (Wallcraft, 2009; Wallcraft & Nettle, 2009). At the same time, multiple reports have been issued in the past decade which indicate that recovery-orientated systems and services are essential (Carroll et al., 2006). The Institute of Medicine's Quality Chasm series (IOM, 2006) points to service improvement needs and the President's New Freedom Commission on Mental Health (NFC, 2003) details the needed policy changes (Carroll et al., 2006). These reports indicate that consumer involvement is essential to improved service systems and outcomes, and reflect recovery values in many of their findings and recommendations (Carroll et al., 2006).

There is a common saying in the consumer movement about recovery: 'We are the evidence' (NCMHR, 2011). There are layers to the meaning of this: The first is that the construct of recovery needs no definition or measurement in order to be 'true'. Individuals have lived it and know it from a perspective that only requires an experiential understanding. The second layer is the capacity of consumers to have a dialogue with one another to discover and begin to label common elements in their individual and collective experience. The next layer requires consumers who have experienced recovery to communicate their knowledge to providers, family members, and others they interact with on an interpersonal level. The final layer is a definition of recovery that can be clearly articulated and quantified as a measurable construct. This multi-layered understanding of recovery from implicit understanding to measurable construct has implications for how we design research studies, develop and implement services as well as how we shape our expectations and standards.

We have more opportunities than ever to expand recovery-orientated practice and alternatives to traditional mental health services. Predictive validity is hard to establish between recovery-orientated systems (or any mental health services/systems) and recovery outcomes. Consumers acknowledge this:

Formal services may or may not support or influence recovery. Some people recover without formal services, some people recover despite poor services, while others attribute recovery, in part, to formal services. The role that formal helping systems play in recovery must be placed in the context of other factors that support or hinder recovery. (Onken et al., 2002)

Because individuals have experienced recovery despite many of the traumas and abuses of the mental health system, it could be argued that formal systems are not always needed to foster recovery. Research has shown that recovery can be independent of the mental health system (Bernard, 2000).

Another characteristic of the consumer movement and recovery practice in the USA today is reflected in the growing acceptance and value of self-help and peer support services – both those that are provided in traditional mental health service settings alongside providers, and

in independent peer-operated programmes. Peer support is a process of bringing mutual support and shared responsibility for recovery to relationships between peers with lived experience of mental health recovery. Peer support is one of the ten components of recovery identified by SAMHSA. They define peer support as: ‘including the sharing of experiential knowledge and skills and social learning ... Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.’

The Centers for Medicare and Medicaid (CMS) is the federal agency responsible for the USA’s public insurance safety net for the elderly, poor and disabled. CMS has demonstrated increasing support for the use of such services under state Medicaid plans (Mann, 2010), and has issued guidance for the development and implementation of peer support services in recent years (Smith, 2007). A recent letter to state Medicaid directors states:

[Peer support] is an evidence-based mental health practice that States may use to expand opportunities for meaningful community inclusion. Qualified peer support providers assist individuals with their recovery from mental health and substance use disorders. CMS recognizes that the experiences of peer support providers can be an important part of effective treatment systems. (Mann, 2010, p. 5)

This statement speaks to the use of trained and state-certified peers, often referred to as certified peer specialists (CPS) in traditional mental health service settings. Twenty-five states now have reimbursement mechanisms for CPSs under Medicaid (Daniels et al., 2010). Medicaid is one of the largest payers for mental health services in the USA (NAMI, 2010). However, there are some drawbacks to Medicaid coverage of peer specialists, notably the need for peers to be supervised by a ‘mental health professional’ and the possible medicalization of peer support (Hermann et al., 2004).

The other venue for peer support is through peer-operated programmes and organizations. It is estimated that there are thousands of peer support organizations in the USA (Goldstrom et al., 2006). Mental health peer-operated organizations have been defined as ‘programs, businesses, or services controlled and operated by people who have received mental health services. With limited exceptions, staff also consists of people who have received mental health services (Goldstrom et al., 2006, p. 95). Most peer-operated organizations engage in advocacy, provide a venue for mutual support groups, do community outreach, and offer opportunities for social and recreational activities (Goldstrom et al., 2004). Studies of expert opinion on critical ingredients of peer-operated MH organizations show that promoting the belief that recovery is possible is rated most essential for the organizations’ fidelity to the model (Holter et al., 2004). This makes them unique from traditional mental health services. Recently, the SAMHSA established consumer-operated service programmes as an evidence-based practice, and released the *Consumer-Operated Services Evidence-Based Practices Toolkit* (Campbell, 2009).

Peer support plays an important role in the continuum of recovery-orientated care for individuals with mental illnesses (NFC, 2003; Office of the Surgeon General, 1999). More informal mental health peer support has existed since the 1970s (Chamberlin, 1978), but only within the last decade have trained peer support specialists and peer-operated organizations blossomed into an integral part of our public mental health service system.

However, some are concerned about professionalizing peer support services. Professionalizing peer support means becoming certified, operating under state standards, partnering with traditional providers, and accepting reimbursement conditional on medical necessity from managed care companies. More peers are becoming certified and working as CPSs in traditional settings, peer-run service organizations are proliferating, and yet peers



may want to maintain the grassroots and organic nature of peer support. Some believe this is not necessarily the best path for the consumer movement:

Indeed, some consumers believe that professionalization and the adoption of new practices essential for partnering with traditional mental health systems present a threat to the future of peer-run programs in general. (Bagby et al., 1995)

There are risks and benefits to the quality and integrity as a source of recovery support if peer support becomes more integrated in the service system.

### **Future trends: Opportunities and threats**

With the 2010 passage of the Patient Protection and Affordable Care Act (ACA – also known as the healthcare reform law) the entire health service delivery system is poised for unprecedented change. The Act is a large and far-reaching attempt to substantially reform the overall US healthcare system. The ACA has provided our healthcare system with the opportunity for significant reforms in quality of care, cost-containment, and models of service delivery. One predictable outcome will be the expansion of Medicaid — a federal and state partnership providing health insurance and bene-fits largely to the poor and disabled. Medicaid is expected to be one of the key strategies for insuring the large segment of the population who now have no coverage. However, there are no crystal balls and yet pending judicial review and decisions by individual states may substantially alter plans for implementation of the law.

Undoubtedly, healthcare reform will have an impact on recovery-orientated practice. The most important parts of the ACA for mental health will be provisions relating to health homes, integration of physical and behavioural healthcare, wellness promotion grant programmes and activities, emphasis on shared decision-making, and expansion of Medicaid (Leaf et al., 2012). Although the implementation of these components is as yet unclear, it is unquestionable that they will impact mental health services. While these are changes welcomed by many, there is real concern that there will be a ‘re-medicalization’ of mental health and the values and principles of recovery practice will get lost in the process. Worse yet, is the concern that funding focused on recovery-orientated practice in the specialty mental health system may be lost or redirected into general healthcare.

It is clear that peer-operated organizations and other peer services have succeeded in mental health because peers are in a unique position to promote recovery and wellness through lived-experience approaches to support individuals with mental disorders that are based on empowerment, self-direction, and mutual relationships. However, little is known about how they will adapt to healthcare reform. Expansion of Medicaid may be one of the greatest challenges for peer-run organizations. Peers may be resistant to facets of Medicaid participation such as losing the mission of promoting recovery under a non-medical model by complying with medical necessity criteria, and the fear that peers will have to sacrifice their role as advocates for recovery-orientated alternatives (Adler et al., 2010).

The Assistant Secretary for Planning and Evaluation (ASPE) estimates that 5.4 million individuals with a mental health or substance abuse disorder will gain insurance coverage through Medicaid expansion (Donohue, 2010). The ACA also promotes the integration of mental and physical health and wellness in anticipation of the needs of this newly eligible but untreated population. This has led to more discussions about programmes that promote physical wellness as an important component of recovery.

The mental health field and recovery practice may have something special and unique to offer to the larger healthcare enterprise. Drawing from the work of Wagner and others, there is increasing recognition of the importance of self-management in promoting successful

overall health outcomes, and the mental health field has come to learn about the unique value and contribution of peers in promoting engagement, understanding and motivation towards better selfcare and outcomes (Coleman et al., 2009).

The increasing recognition of the burden and cost for the healthcare delivery system in providing services for people with multiple chronic conditions and the lack of adequate mental healthcare for these individuals is a real opportunity for mental health providers – including peers – to promote recovery-orientated and wellness outcomes. There are already efforts at training peer wellness coaches, who can assist people in developing health-related goals and maintaining a healthy lifestyle (Swarbrick et al., 2011). Peer-operated organizations are already providing peer support for wellness (Swarbrick et al., 2011) – a role that needs to be expanded as whole health becomes an important dimension of recovery.

Peers want to be recognized as professionals with standards and as a legitimate part of mental healthcare (Hermann & Palmer, 2002) and perhaps healthcare overall. But exactly how the consumer/peer movement will find ways for peer support to be integrated into the system while still remaining true to core values remains uncertain. Peer support is seen as essential to a recovery-orientated and consumer-driven system, and influencing the entire mental health system to be more recovery-orientated should be as important as creating a separate, respected discipline or legitimate alternative treatments.

What the mental health system needs to do is to support the reality of individuals' existence as more than services users, more than consumers, more than people who need to be pulled and pushed out of psychiatric disability into recovery. This is not a vision and it is not an ideology – it is an acceptance of what we know to be true: that individuals who struggle to connect with their existence, and are labelled 'mentally ill' are alive and human whether they use the treatment system, are helped by it, are abused by it, reject it, or feel stifled by its fundamentally flawed means of 'engaging' consumers in care. What individuals labelled with mental health diagnoses need are the tools to engage in their own lives and the ability to have a dialogue about their quest for recovery among the community. It is essential that this be preserved in any overall healthcare reform effort – but there is genuine risk it will not.

Recovery is a process, but if we're going to 'transform' our system, it should be around an outcome such as optimal mental health and whole person wellness. Otherwise we are redesigning a broken system around the idea that everyone is 'doing their best' and not accountable to any standards except trying.

## Promoting an international dialogue

All too often notions of American exceptionalism (Cox & O'Neil, 2008) result in the USA isolating itself on matters of policy and practice from the rest of the world. Our healthcare system is far different from that in any other developed country. While the recovery movement has grown strong here, and recovery-orientated practices such as shared decision-making and peer support are gaining recognition, validity and popularity – particularly with the passage of the 2010 Health Care Reform Bill – the USA too often is not sufficiently engaged with other developed and developing countries in our approach to recovery. For example, some cross-national studies estimate that recovery-related outcomes are more prevalent in developing countries (Hopper & Wanderling, 2000). In addition, other developed countries, such as Finland (Seikkula et al., 2001) and New Zealand (O'Hagan, 2004) have much to offer us in terms of new approaches to recovery, community integration, and alternatives to the medical model. At the same time there are potentially valuable lessons to be learned from the US recovery movement – particularly the political influence of the consumer movement – to inform system development in other countries.

For instance, in Hong Kong the recovery movement is not as well developed as elsewhere (Tse, this issue, pp. 40 – 47) and does not have the decades long history of the US recovery movement. The USA must become more engaged in dialogue with other nations as recovery-orientated practices spread across the globe, to both share our own experience as well as learn from others.

## References

- Adams, N.; Grieder, D. *Treatment Planning for Person-Centered Care: The Road to Mental Health and Addiction Recovery: Mapping the Journey for Individuals, Families and Providers*. San Diego, CA: Academic Press; 2005.
- Adler, D.; Bergeson, S.; Brown, M.; Fox, P. *The Next Step to Sustainability: Expanding our Family/Consumer Run Organization's Impact by Joining a Managed Care Organization Network*. Rockville, MD: OptumHealth Public Sector & Child, Adolescent and Family Branch, CMHS/SAMHSA; 2010.
- APA. *Position Statement on the Use of the Concept of Recovery*. Washington, DC: American Psychiatric Association; 2005.
- Anthony WA. Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*. 1993; 16:11.
- Bagby RM, Joffe RT, Parker JDA, Kalembo V, Harkness KL. Major depression and the five-factor model of personality. *Journal of Personality Disorders*. 1995; 9:224–234.
- Barker P. The Tidal Model: Psychiatric colonization, recovery and the paradigm shift in mental health care. *International Journal of Mental Health Nursing*. 2003; 12:96–102. [PubMed: 12956020]
- Bernard, HR. *Social Research Methods : Qualitative and Quantitative Approaches*. Thousand Oaks, NJ: Sage; 2000.
- Brown, P. The Mental Patients' Rights Movement. In: Brown, P., editor. *Mental Health Care and Social Policy*. Boston: Routledge; 1985. p. 187-212.
- Calabrese, J.; Corrigan, P. Beyond dementia praecox: Findings from long-term follow-up studies of schizophrenia. In: Ralph, RO.; Corrigan, PW., editors. *Recovery in Mental Illness: Broadening our Understanding of Wellness*. Washington, DC: American Psychological Association; 2005. p. 63-84.
- Campbell-Orde, T.; Chamberlin, J.; Carpenter, J.; Leff, HS. *Measuring the Promise: A Compendium of Recovery Measures*. Vol. Volume II. Cambridge, MA: NEvaluation Center, HSRI; 2005.
- Campbell, J. *Federal Multi-Site Study Finds Consumer-Operated Service Programs are Evidence-Based Practices*. St Louis, MO: Missouri Institute of Mental Health; 2009.
- Carroll CD, Manderscheid R, Daniels AS, Compagni A. Convergence of service, policy, and science toward consumer-driven mental health care. *Journal of Mental Health Policy and Economics*. 2006; 9:185–192. [PubMed: 17200595]
- Chamberlin, J. *On Our Own: Patient-Controlled Alternatives to the Mental Health System*. New York: Hawthorn; 1978.
- Chamberlin J. The Ex-Patients' Movement: Where we've been and where we're going. *Journal of Mind and Behavior*. 1990; 11:323–336.
- Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the chronic care model in the new millennium. *Health Affairs*. 2009; 28:75–85. [PubMed: 19124857]
- Corrigan PW, Salzer M, Ralph RO, Sangster Y, Keck L. Examining the factor structure of the Recovery Assessment Scale. *Schizophrenia Bulletin*. 2004; 30:1035–1041. [PubMed: 15957202]
- Cox D, O'Neil A. The unhappy marriage between international relations theory and international law. *Global Change Peace and Security*. 2008; 20:201–215.
- Daniels, A.; Grant, E.; Filson, B.; Powell, I.; Fricks, L.; Goodale, L. *Pillars of Peer Support: Transforming Mental Health Systems of Care Through Peer Support Services*. Atlanta GA: Carter Center; 2010.
- Davidson L, O'Connell M, Tondora J, Styron T, Kangas K. The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric Services*. 2006; 57:640–645. [PubMed: 16675756]

- Donohue, J.; Garfield, R.; Lave, J. The Impact of Expanded Health Insurance Coverage on Individuals with Mental Illnesses and Substance Abuse Disorders. Washington, DC: Assistant Secretary for Planning and Evaluation, Department of Health and Human Services; 2010.
- Frank, A. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago, IL: University of Chicago Press; 1995.
- Goldman HH, Adams NH, Taube CA. Deinstitutionalization: The data demythologized. *Hospital and Community Psychiatry*. 1983; 34:129–134. [PubMed: 6860396]
- Goldman HH, Glied SA, Alegria M. Mental Health in the Mainstream of Public Policy: Research Issues and Opportunities. *American Journal of Psychiatry*. 2008; 165:1099–1101. [PubMed: 18765490]
- Goldstrom, I.; Campbell, J.; Rogers, J.; Lambert, D.; Blacklow, B.; Henderson, M.; Manderscheid, R. Mental health consumer organizations: A national picture. In: Manderscheid, R.; Berry, J., editors. *Mental Health, United States*. Rock-ville, MD: Department of Health and Human Services; 2004. p. 247-255.
- Goldstrom I, Campbell J, Rogers J, Lambert D, Blacklow B, Henderson M, Manderscheid R. National estimates for mental health mutual support groups, self-help organizations, and consumer-operated services. *Administration and Policy in Mental Health and Mental Health Services Research*. 2006; 33:92–103. [PubMed: 16240075]
- Harding C, Brooks G, Ashikaga T, Strauss J, Breier A. The Vermont longitudinal study of persons with severe mental illness, II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry*. 1987; 144:727–735. [PubMed: 3591992]
- Hermann R, Palmer H, Leff HS, Shwartz M, Provost S, Chan J, Lagodmos G. Achieving consensus across diverse stakeholders on quality measures for mental healthcare. *Medical Care*. 2004; 42:1246–1253. [PubMed: 15550805]
- Hermann R, Palmer RH. Common ground: A framework for selecting core quality measures for mental health and substance abuse care. *Psychiatric Services*. 2002; 53:281–287. [PubMed: 11875220]
- Holter MC, Mowbray CT, Bellamy CD, MacFarlane P, Dukarski J. Critical ingredients of consumer run services: Results of a national survey. *Community Mental Health Journal*. 2004; 40:47–63. [PubMed: 15077728]
- Hopper K, Wanderling J. Revisiting the developed versus developing country distinction in course and outcome in schizophrenia: Results from ISoS, the WHO collaborative followup project. *Schizophrenia Bulletin*. 2000; 26:835–846. [PubMed: 11087016]
- IOM. *Improving the Quality of Health Care for Mental and Substance-Use Conditions*. Washington, D.C.: National Academies Press; 2006.
- Laing, R. *The Divided Self: An Existential Study in Sanity and Madness*. New York: Pantheon Books; 1962.
- Leaf, PJ.; Ostrow, L.; Manderscheid, R.; Shern, D.; Eaton, WW. Progress made but much more to be done. In: Eaton, WW., editor. *Public Mental Health*. New York: Oxford University Press; 2012.
- Manderscheid R. Personal Communication with L. Ostrow. 2008
- Mann, C. Dear State Medicaid Director, Re: Community Living Initiative. Baltimore, MD: Department of Health and Human Services, Centers for Medicare and Medicaid Services; 2010.
- McLean A. From ex-patient alternatives to consumer options: Consequences of consumerism for psychiatric consumers and the ex-patient movement. *International Journal of Health Services*. 2000; 30:821–847. [PubMed: 11127026]
- NAMI. *Public Mental Health Service Funding: An Overview*. Arlington, VA: National Alliance on Mental Illness; 2010.
- NCMHR. National Coalition for Mental Health Recovery Statement of Purpose. 2011. <http://www.ncmhr.org/purpose.htm>
- NFC. *Achieving the Promise: Transforming Mental Health Care in America*. Rockville, MD: New Freedom Commission, Department of Health and Human Services; 2003.
- Nielsen-Bohlman, L. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press; 2004.

- NIMH. A Network for Caring: The Community Support System Program of the National Institute of Mental Health. Rockville, MD: National Institute of Mental Health; 1982.
- O'Hagan M. Recovery in New Zealand: Lessons for Australia. *Australian E-Journal for the Advancement of Mental Health*. 2004; 3:1–3.
- Office of the Surgeon General. *Mental Health: A Report of the Surgeon General*. Rockville, MD: Department of Health and Human Services; 1999.
- Onken, S.; Dumont, J.; Dornan, D.; Ralph, R.; Ridgway, P. *Mental Health Recovery: What Helps and What Hinders? Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*. Alexandria, VA: National Association of State Mental Health Program Directors, National Technical Assistance Center; 2002.
- Onken, S.; Dumont, J.; Ridgway, P.; Dornan, D.; Ralph, RO. *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. Alexandria, VA: National Association of State Mental Health Program Directors, National Technical Assistance Center; 2003.
- Rissmiller DJ, Rissmiller JH. Evolution of the antipsychiatry movement into mental health consumerism. *Psychiatric Services*. 2006; 57:863–866. [PubMed: 16754765]
- SAMHSA. *National Consensus Statement on Mental Health Recovery*. Rockville, MD: US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services; 2004.
- Scheff, T. *Being Mentally Ill: A Sociological Theory*. New York: Aldine de Gruyter; 1966.
- Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist Psychology*. 2001; 14:247–265.
- Smith, DG. *Dear State Medicaid Director, SMDL #07–011*. Baltimore, MD: Department of Health and Human Services, Centers for Medicare and Medicaid Services; 2007.
- Swarbrick M, Murphy AA, Zechner M, Spagnolo AB, Gill KJ. Wellness Coaching: A New Role for Peers. *Psychiatric Rehabilitation Journal*. 2011; 34:328–331. [PubMed: 21459751]
- Szasz, T. *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*. New York: Harper & Row; 1974.
- Tomes N. The patient as a policy factor: A historical case study of the consumer/survivor movement in mental health. *Health Affairs*. 2006; 25:720–729. [PubMed: 16684736]
- Van Tosh L. The Evolution of the Consumer Movement. *Psychiatric Services*. 2006; 57:1215–1216. [PubMed: 16870984]
- Wallcraft, J.; Nettle, M. History, context and language. In: Wallcraft, J.; Schrank, B.; Amering, M., editors. *Handbook of Service User Involvement in Mental Health Research*. Oxford: Wiley; 2009.
- Ware NC, Hopper K, Tugenberg T, Dickey B, Fisher D. Connectedness and citizenship: Redefining social integration. *Psychiatric Services*. 2007; 58:469–474. [PubMed: 17412847]